Patient Preference and Adherence

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ORIGINAL RESEARCH

Perceived Barriers and Supports to Medication Adherence in Type 2 Diabetes: A Qualitative Study of Patients with and without a Zero-Dollar Copay Health Plan Benefit

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Introduction: Medication adherence among individuals with type 2 diabetes (T2D) remains a critical determinant of disease management and health outcomes. While cost-sharing reductions such as a $0 copay (ZDC) for drugs are used to improve adherence, less is known about how patients with and without such benefits perceive barriers to adherence and what strategies may further support consistent medication use. This study explored barriers and facilitators to medication adherence among health plan members with T2D, including perceived barriers and potential strategies to enhance medication adherence.

Methods: This qualitative study was conducted as part of a larger mixed-methods investigation examining medication adherence among individuals with T2D. The research team conducted semi-structured interviews with health plan members diagnosed with T2D. An interview guide was co-developed by a multidisciplinary team that included health services researchers, patients, health plan leaders, and clinicians, ensuring relevance and clarity across stakeholder groups. Interviews were conducted between June and December 2024, audio-recorded with participant consent, and transcribed verbatim. A descriptive qualitative analysis was conducted using both inductive and deductive approaches. Three members of the research team independently applied open coding techniques to the transcripts, iteratively refining themes through discussion and consensus. NVivo software was used to facilitate data organization and analysis.

Results: In total, we interviewed 21 Louisiana Blue, a reginal health insurance plan, beneficiaries (11 with the ZDC benefit and 10 without the ZDC benefit). We identified four themes from the interviews – themes were the same across the two groups - 1) Costly medication copays were described as a key barrier to taking medications as prescribed; 2) memory aids, family support, and routines were identified as strategies to maintain adherence; 3) health care providers were crucial in educating members about their medication, including responding to concerns such as side effects; and 4) members' perceptions of pharmaceutical companies were coupled with concerns about medication costs. Barriers and facilitators were largely similar among participants with and without the zero-dollar copay benefit.

Conclusion: Findings suggest that eliminating copayments alone does not resolve the multifaceted barriers to adherence, and that limited awareness of benefit status may further constrain the impact of such programs; introduction.

Plain Language Summary: Managing type 2 diabetes often requires people to take medications regularly, but many patients have difficulty doing so. One common barrier is the cost of medications. Some health plans try to improve adherence by removing out-of-pocket costs, such as offering a **$0 copay benefit**. However, it is not well understood how patients experience barriers to taking their medications or what strategies might help them stay on track.

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This study explored these issues by interviewing members of Louisiana Blue who have type 2 diabetes. Between June and December 2024, researchers conducted interviews with 21 health plan members, including 11 who had a $0 copay benefit and 10 who did not. The interview questions were developed with input from researchers, clinicians, patients, and health plan leaders. The research team analyzed the interview transcripts to identify common themes.

Four main themes emerged, and they were similar for people with and without the $0 copay benefit. However, many participants were not fully aware of which medications were covered by the $0 copay benefit, which may have influenced how they experienced medication costs.

First, many participants said that high medication costs made it difficult to take their medications as prescribed. Second, people described strategies that helped them remember their medications, such as using reminders, building routines, and relying on family support. Third, health care providers played an important role in explaining medications and addressing concerns, including possible side effects. Finally, some participants expressed concerns about pharmaceutical companies and drug pricing.

Overall, while reducing medication costs may help improve adherence, other factors also matter. Supporting patients with reminders, strong communication with providers, and broader social support may help people with diabetes take their medications more consistently.

Keywords: medication adherence, type 2 diabetes, qualitative, barriers, facilitators

Introduction

Type 2 diabetes (T2D) is a chronic condition characterized by insulin resistance and hyperglycemia. T2D affects approximately 12% of the US population, with even higher prevalence in certain states, such as Louisiana, where nearly 14% of adults are living with the disease.[1,2] People living with T2D are at a higher risk of developing severe health complications, including cardiovascular disease, kidney failure, neuropathy, and retinopathy.[3] In part due to these complications, diabetes has a crude death rate of 120.3 deaths per 100,000 people where diabetes was listed as a contributing cause of death, becoming significantly higher for people with uncontrolled diabetes.[1,4]

Achieving a hemoglobin A1c level (HbA1c) below 7% is the primary goal of T2D care management, and consistent medication adherence plays a crucial role in this.[5] Medication adherence is strongly associated with improved glycemic control, fewer hospitalizations, reduced risk of complications, better quality of life, and lower healthcare costs.[6,7] Medication adherence is a complex issue shaped by various social and behavioral factors, including influences from patients, health care providers, and the health care system.[8,9] One of the primary barriers to adherence is cost.[10] Patients with high out-of-pocket expenses c ration medication, delay refills, or discontinue treatment altogether, exacerbating their condition and increasing health care use. Addressing cost-related barriers is crucial to improving adherence and ensuring optimal diabetes management.

To address cost-related nonadherence, Louisiana Blue, a regional health insurance plan, implemented a $0 copay (ZDC) program that eliminates both copayments and deductibles for a subset of medications used to treat chronic conditions, including diabetes. However, the benefit applies only to selected drugs and is available through certain plan types, with coverage varying by employer-sponsored plan design. As a result, not all diabetes medications are included in the program, which may limit the extent to which the ZDC benefit reduces patients' overall out-of-pocket costs. A list of eligible diabetes drugs can be found in Supplemental Material 1. Given Louisiana's high burden of diabetes and associated health disparities, examining how patients experience medication adherence within a regional health plan context is particularly important for informing local policy and program design.

However, there are several noncost–related barriers to medication adherence for T2D treatments. Individual barriers include concerns about side effects, perceived lack of necessity, and restraints in daily routine.[11] Health system barriers include poor communication between health care providers and patients, problems with prescriptions, and pharmacy issues.[12] These are just a few examples; many additional barriers may hinder medication adherence.

While strategies like the ZDC program aim to address barriers to medication adherence, it remains unclear whether they are sufficient to overcome the broader challenges patients face. Although previous research has examined the impact of financial assistance programs on adherence, less is known about how patients perceive and experience adherence barriers in the presence or absence of such benefits. In particular, it is unclear how patients understand and navigate benefit design, and how financial relief interacts with behavioral and health system barriers to influence medication use. This study addresses that gap by examining the lived experiences and perceptions of patients with T2D who were enrolled in or excluded from a ZDC initiative. Specifically, we sought to understand whether perceived adherence barriers differed by copay benefit status and to identify the financial and nonfinancial factors that shaped medication use across both groups.

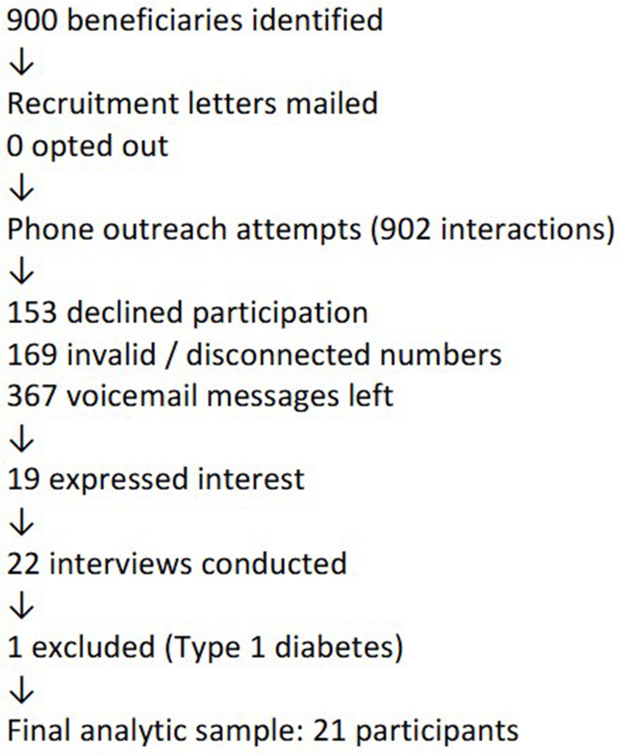
By documenting patients' perspectives through qualitative interviews, this study aimed to understand perceived barriers to adherence, which might help inform future strategies to improve adherence.

Methods

This qualitative study is part of a complementary mixed-methods approach through the Louisiana Experiment Addressing Diabetes Zero Dollar Copay (LEAD-ZDC) study. The broader LEAD-ZDC study evaluates the zero-dollar copay program using the RE-AIM implementation framework (Reach, Effectiveness, Adoption, Implementation, and Maintenance). Within this framework, the qualitative component aimed to better understand patient perspectives on medication adherence barriers and facilitators that may influence the real-world implementation and effectiveness of the program.[13,14] The overall goal is to assess the impact of Louisiana Blue's ZDC program using quantitative and qualitative methods. Previous parts of the LEAD-ZDC study informed the interview guide.[15] This study followed the Standards for Reporting Qualitative Research (SRQR) Guidelines for reporting on qualitative research.[16] We used a descriptive qualitative approach employing thematic analysis to explore patient experiences and perspectives related to medication adherence.

Health services researchers, patients, health plan leadership, and clinicians collaboratively developed discussion guides for interviews with health plan members who have T2D. The interview guide (see Supplemental Material 2) was administered by two researchers on the LEAD-ZDC team. Previous parts of the LEAD-ZDC study informed the discussion guide.[15] The discussion guide consisted of vignettes (about a person named Danielle), or short hypothetical scenarios, designed to elicit participants' beliefs and perceptions without requiring them to disclose personal experiences with sensitive topics. Vignettes were used to reduce social desirability bias and encourage more open discussion, as participants may feel more comfortable responding to hypothetical situations.[17] Participants were also asked to reflect on the experiences of others they know living with diabetes. It is important to note that while the vignette approach may have shaped the discussion, direct questions revealed that several participants were genuinely unaware of their ZDC benefit status, highlighting a gap in program communication and awareness. Instead, we asked if members had awareness of the ZDC program. The discussion guide can be found in Supplemental Material 2. Additionally, demographic information was collected to understand the characteristics of those interviewed to enable assessment of the generalizability of study results. Two pilot interviews were conducted before the study to refine the interview guide and were not included in the analysis.

To recruit participants, Louisiana Blue created a list of 900 random beneficiaries with, including individuals enrolled in plans with and without the ZDC benefit (Figure 1). An initial recruitment letter describing the study was mailed to these individuals with study details and information on how to opt out of further contact about the study. Of the 900 beneficiaries contacted, 0 opted out of further contact. Of the 900 beneficiaries contacted, 153 declined participation, 169 phone numbers were invalid or disconnected, and 367 outreach attempts resulted in voicemail messages requesting a callback. Nineteen individuals expressed interest in participating in the study and 22 interviews were conducted. One participant was excluded after reporting a diagnosis of type 1 diabetes rather than type 2 diabetes, resulting in a final analytic sample of 21 participants. The ZDC group included members enrolled through firms that used Louisiana Blue as a traditional insurer—meaning Louisiana Blue assumed both financial and administrative responsibility. These members were automatically enrolled in the ZDC program if they had at least one of the following conditions: diabetes, hypertension, heart disease, lung disease, or mental illness. In contrast, the comparison group consisted of members insured through firms with administrative services only (ASO) agreements, where the employer bore financial risk and Louisiana Blue handled claims. Self-selection into the ZDC program was not permitted. These structural differences between plan types may reflect underlying employer or socioeconomic characteristics. Recruitment was designed to



900 beneficiaries identified
↓
Recruitment letters mailed
0 opted out
↓
Phone outreach attempts (902 interactions)
↓
153 declined participation
169 invalid / disconnected numbers
367 voicemail messages left
↓
19 expressed interest
↓
22 interviews conducted
↓
1 excluded (Type 1 diabetes)
↓
Final analytic sample: 21 participants

Figure 1 Recruitment Flow-Chart.

include participants with and without the ZDC benefit, and efforts were made to ensure representation from both groups. All participants received a $50 Amazon gift card for their time. Our recruitment target was 20–30 participants. We ceased recruitment at 22, as data saturation had been achieved. Saturation was defined as the point in which additional interviews no longer generated new codes or themes. Saturation was assessed across the full sample (not by group) and was observed during the final interviews when no new thematic categories emerged.[18] Participants were sent detailed information on the study and the consent document before the interviews. Researchers documented their verbal consent before the study and the consent included permission to publish anonymized responses/direct quotes. The Tulane University Institutional Review Board approved the study under application no. 2020–1986. And the study complies with the Declaration of Helsinki. One participant was excluded from analysis as they had type 1 and not type 2 diabetes.

Data collection and analysis was led by a core team of three trained public health researchers with prior experience in qualitative methods and familiarity with the study context between June and December 2024. Based on participant convenience, interviews were held over Zoom or by phone and lasted between 15 and 45 minutes. To promote consistency in data collection, the research team participated in joint training sessions to establish a shared understanding of the interview approach and study objectives. The interview guide was piloted and refined based on feedback from patient partners and the study steering group to ensure clarity, relevance, and appropriateness.

For all interviews, researchers recorded and took notes, and the interview recordings were transcribed. Additionally, transcripts were de-identified and reviewed by the researchers for accuracy. Throughout data collection, interviewers maintained reflexive memos to document their perspectives, assumptions, and potential influences on the research process, recognizing that researcher positionality can shape both data collection and interpretation.

The transcripts were managed using NVivo software to facilitate analysis and data management. Inductive and deductive approaches were used for coding. Three researchers independently reviewed transcripts and applied open coding to the to generate an initial set of codes. The research team then met regularly to compare interpretations, resolve discrepancies through, and iteratively refine the coding framework. Trough this process, related codes were grouped into candidate themes that reflected patterns across participant responses. Coding consistency was ensured through independent coding by multiple researchers and iterative consensus discussions during which discrepancies were reviewed and resolved collaboratively. Through this process, related codes were grouped into candidate themes that reflected patterns across participant responses. Themes were refined through repeated discussion among the research team and by revisiting the raw transcripts to ensure alignment with participants' language and perspectives. Due to the qualitative nature of the study and small sample sizes, statistical tests were not performed to compare groups or for any other analysis Similarly, the study captures perceptions rather then longitudinal outcomes and statistical power calculations were not possible due to the qualitative design.

The research team included health services researchers and collaborators from academic institutions, a health plan, and public health organizations. Because some team members were affiliated with institutions connected to the health plan context, the team incorporated reflexive discussions throughout the analytic process to minimize potential interpretive bias. Coding decisions were made collaboratively, and themes were reviewed within a multidisciplinary steering committee that included clinicians, researchers, and a patient partner to ensure that interpretations remained grounded in participant perspectives.

Results

Demographic Backgrounds

Table 1 presents demographics for 21 Louisiana Blue beneficiaries (11 with ZDC, 10 without). Most were female (71%) and lived in urban areas (71%). The average age was 57.14 years, and participants had diabetes for an average of 10.7 years. ZDC participants had a longer diabetes duration (12.3 vs 8.8 years). Educational attainment varied, with more ZDC participants attending college or graduate school (54%) compared to non-ZDC participants (40%). Structural differences between plan types (eg, employer-sponsored ASO vs traditional plans) may reflect underlying socioeconomic or employment-related characteristics.

Table 1 Participant Characteristics

		ZDC (n=11)	**Non-ZDC (n=10)**	**Total (n=21)**
Sex	Female	73% (8)	70% (7)	71% (15)
	Male	27% (3)	30% (3)	29% (6)
Race	White	45% (5)	50% (5)	52% (11)
	African American	55% (6)	40% (4)	43% (9)
	Not Specified	0 (0%)	10% (1)	5% (1)
Education	High School	27% (3)	20% (2)	24% (5)
	Some College	9% (1)	30% (3)	19% (4)
	College Graduate	36% (4)	40% (4)	38% (8)
	Graduate School	18% (2)	0% (0)	10% (2)
	Not specified	9% (1)	10% (1)	10% (2)
Residence	Urban	64% (7)	80% (8)	71% (15)
	Rural	36.% (4)	20% (2)	28.% (6)
Average Age (Years)		55.6	58.8	57.1
Average Time Since Type 2 Diabetes Diagnosis (Years)		12.3	8.8	10.7

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Overview of Themes

Participants described a range of influences shaping medication adherence that spanned financial, behavioral, interpersonal, and system-level factors. These themes reflected the multilevel nature of medication adherence and included financial barriers related to medication cost, behavioral strategies such as routines and reminders, the role of healthcare providers in supporting adherence, and broader concerns about pharmaceutical pricing and trust in the healthcare system.

Four major themes emerged from the analysis, representing financial barriers, behavioral adherence strategies, health system influences, and broader concerns related to medication pricing and trust: (1) high medication copays as a key barrier to adherence, (2) the use of memory aids, family support, and routines to support adherence, (3) the critical role of healthcare providers in medication education and management, and (4) concerns about pharmaceutical companies and drug pricing. These themes are further illustrated by participant quotes, which highlight key insights and perspectives.

Instead, participants across both groups described similar financial, behavioral, and system-level challenges influencing medication adherence.

Notably, we did not find substantial differences in adherence barriers between ZDC and non-ZDC participants. Instead, participants across both groups described similar financial, behavioral, and system-level challenges influencing medication adherence.

Few participants explicitly reflected on the perceived value or utility of the ZDC program itself, or did not express awareness of being in the program. Instead, both groups expressed sentiments related to all four themes. We return to this point in the Discussion.

Theme 1: Costly Medication Copays Reported by Health Plan Members Made It Difficult to Adhere to Medications

Based on interviews, regardless of ZDC-program status, participants reported that medication copays were a significant barrier to adherence due to high out-of-pocket costs – encompassed by both co-pays and deductibles. These costs further caused challenges when there were unanticipated changes in coverage. Finally, participants reflected on the broader challenges of cost and accessibility, especially pertaining to specific branded drugs and the role of pharmaceutical companies in shaping costs.

For instance, one participant described the role of her deductible, which she felt was already high:

> If my deductible was higher than it is – which is already high because it's a high deductible, it's $3300 a year – if it was a $5000 or $10,000 deductible, I don't know if I could get the medicine for that many months until I met my deductible - NonZDC1

When asked how much a drug would cost in co-pays to be considered expensive, answers ranged from $50 to several hundred dollars based on each participant's specific circumstances. However, there was a consensus that high copays could lead to poor adherence, with participants recounting both their own experiences with or without the ZDC benefit, anecdotes from others close to them, and reflections regarding hypothetical persons facing medication challenges. These experiences were connected to the recounting of strategies to manage budgets or competing expenses, including delaying refills, stockpiling medication, or foregoing treatment altogether. The following examples illustrate this finding.

> We actually ended up taking [my daughter with diabetes] off [a drug] because we couldn't afford it. – ZDC1

> Well, that's the deal. The higher [cost] the drug is, the more you have to save if you're in a financial bind with it… If you have to stockpile a drug or two, you might feel like you have to do that more with the more expensive drugs. -NonZDC10

> It's cost. It's when you go in the grocery store or [a pharmacy] is next to the grocery store, and your grocery bill that was $300 went to $375, and now you don't have the $75 to pick up your medication next door. You choose to feed your family. – NonZDC2

> There was a time when I was on [one medication], and they had paired it with [a drug], and there was some issue with my insurance, and it was hundreds of dollars that I would have had to pay. I didn't get the medicine because I didn't have the money. -ZDC5

Additionally, insurance designs introduced challenges for participants with and without the ZDC benefit. For instance, one participant described how their deductibles reset at the end of the year, making it difficult to afford their medications.

> We're on [an insurance] with huge deductibles and huge out-of-pocket, maximum out-of-pocket. In January, for those three medications, I'd pay $2000 and most people cannot afford that. – ZDC3

Other issues around insurance designs included differences in plan type. For example, one participant said:

> My job recently switched to a [new insurance plan], and that particular one does not pay for a lot of different medicine- NonZDC10

While participants such as the one above showed awareness that changing to a different insurance plan (ie. downgrading to an HMO) led to changes in price, other participants discussed how copays and coverage changed with no explanation or warning, leading to further difficulties affording their medication.

> I had some friends about to pick up [their medication]. I guess something changed on their insurance plan, and they didn't know about [it] or whatever. All of a sudden, the price went way up on some of their meds. They were caught by surprise. - NonZDC6

Moreover, concerns about cost were more prominent in certain types of medications or for certain groups of people. For example, some participants felt that some drugs such as metformin were affordable, several raised concerns about the higher copays for newer, more effective medications such as Glucagon-Like Peptide-1Agonists (GLP-1s).

> I wish the GLP-1s were less expensive. I think they're helpful. I would think that [insurance] would pay for more… so more people who couldn't afford it could be on it. Because typically, it's the demographics of the lower [income] people who make less money who are overweight and do have diabetes that can't—it would be hard for them to come up with $200 a month on their insurance. -ZDC9

Participants reflected on the broader affordability challenges faced by lower-income individuals, even if they themselves were able to manage their out-of-pocket costs. For instance:

> I honestly think it should be a little bit better accessible. I'm getting up in the years here. I might eventually retire. When I retire, damn, that's going to take a lot of my retirement money, paying for all this stuff - ZDC2

> If you're on a fixed income… and you make $35,000 a year, the difference in $100 medication and say a $100 medication to somebody who makes $75,000 a year is a big difference. Everything is relative – ZDC6

Theme 2: In Response to Structural and System-Wide Barriers: Reminders, Family Support, and Routines Were Identified as Strategies to Maintain Adherence

In addition to cost, participants identified multiple other barriers to medication adherence, including issues with refills, difficulty remembering medications, and lifestyle challenges. However, participants identified a variety of strategies that helped them maintain medication adherence, including the use of reminders, support from family members, and the establishment of consistent routines.

One of the primary barriers participants discussed entailed delays in refills. The reasons for delays were sometimes located with the doctor's office or pharmacy, in the case of routine lag times or pharmacy stock-outs. In other cases, patients reported their own challenges in picking up refills after delays or with transportation to the pharmacy. Some, as shown by ZDC8's quote, illustrated an important connection between these delays.

> When [the pharmacy] calls them to refill it, they take forever to refill it. I have to end up calling them, saying, "Yo, guys, I'm calling you because I'm out". Sometimes there's a lag of the doctor's office getting it done - ZDC2

> [Some people] don't have time to get to the pharmacy. After COVID all the pharmacies are closing earlier now. Life gets busy. She may have meetings. She may have kids she's got to deal with. - ZDC2

> An issue is probably finding the time to go pick up the prescription. I'm not sure if [Danielle] has transportation for it. - NonZDC5

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> Sometimes the pharmacy doesn't have the medication in stock, and it takes about two to three days or up to a week for them to get it. Personal experience. Within that timeframe, you just forget about it. It's just happenstance. It's not in your memory to go back within two hours or the following day to pick it up. By the time you remember, you're like, "I know I'm supposed to be taking something else. Oh, let me go", and that's when it comes up. "Let me go and get it then. - ZDC8

Participants identified several solutions they could personally overcome challenges related to refill barriers. Specifically, participants found that they could rely on technology and their social network to help with their concerns. For instance, some pharmacies have apps or other technology-based programs that streamline the refill process.

> That's why it's best if your doctor's office calls it in, even if you drop it off and you're not able to stay to pick it up while it's being filled, it's best to have that reminder with the pharmacy, if you have the app. If they have an app available, make sure that you are a member with that app on your phone, and they will send it to you that way once it's filled - ZDC8

> [A pharmacy] has a really neat function where it automatically notices if you're low, it'll alert me and say, "Hey, your prescriptions that can be filled, do you want to refill them?" "Yes", and then it sends you an alert that the prescription is ready. Probably also doing a three-month refill is helpful - NonZDC5

As mentioned, some participants found that their pharmacies did not have their prescriptions in stock, limiting their access to medications. Strategies including delivery services and social networks helped patients get their prescriptions when transportation was an issue, including a more dramatic instance of social networks facilitating medication access across states

> Well, I know that a lot of drugstores do offer delivery for a fee. – NonZDC9

> Not everybody has that money [for delivery services]. Reach out to neighbors, people, family. It's difficult sometimes when you don't have that support group around you. There's always that Council on Aging. I mean, I know that [my city] has a seniors help group that you can call. - NonZDC9

> I live in Louisiana. With my [prescription] I have a hard time getting it filled here, especially at [a pharmacy]. My sister lives in Texas and I have them send it to—my prescription to a [pharmacy] where my sister lives. I get it that way - NonZDC4

Furthermore, forgetting to take medications emerged as a frequent challenge regardless of cost, access, or ZDC benefit. Several participants described instances where busy schedules, distractions, or changes in routine led to missed doses. In response, many developed personalized strategies including using pillboxes, setting alarms, or placing medications in visible locations to help establish consistent routines.

> I'm a big advocate for alarms on your cellular device. They're mini computers that we carry around. We need to use all the features that are on them. I actually use the labels on my alarms when I'm teaching myself something new, so I think that's a great functionality we all have, just about. - NonZDC2

> Have some medicines that I take in the morning,' and then I have some that I'm supposed to take in the evening. I try to attach a task that I do every morning' to takin' the medication, so that I don't forget… so I know that when I brush my teeth in the morning,' I need to go take my medicine. -NonZDC5

> I have them in my closet, in my walk-in closet with clothes. They are there when I walk in the morning to check my clothes. I'll see them, and I'll take them. Then after dinner when I take a shower, I'll take them again. - ZDC11

> Well, I know that some who was takin' medication, they get those little box to help them each day to remind them, "Yeah, well, I got to take it today because the pills are still there" or "I've taken it because the pill is not there". - ZDC7

As with the previously discussed barriers on refills, social support through family members played an important role with maintaining routines for adherence.

> I have to make my sister remind me. "Remind me to take my [medication] tonight before I go to bed. - ZDC2

> My wife helps me…with the little pill holders that are by the day of the week. -ZDC3

> It’s not just the hands-on help that I get. It’s my entire family supports that, and asks me all the time how it’s goin’ and how my sugar is and et cetera. – ZDC3

Theme 3: Healthcare Providers Played a Critical Role in Mitigating System-Level Barriers to Adherence by Helping Patients Navigate Insurance, Manage Side Effects, and Access Affordable Treatment Options

Participants highlighted how healthcare providers (HCPs) could potentially play a critical role not only in educating members with and without the ZDC benefit about their medications but also in navigating broader system-level barriers to adherence. This included addressing concerns about side effects, assisting with insurance coverage issues, recommending cost-saving alternatives, and helping patients manage complex medication regimens. By acting as intermediaries between patients and the healthcare system, providers helped reduce some of the structural and administrative burdens that can hinder consistent medication use.

Many participants described their providers as trusted sources of information who helped them understand the purpose and importance of their medication. Several reasons for nonadherence included not knowing the purpose of certain medications, or feeling uncertain about how or when to take them. These gaps in understanding often contributed to inconsistent use, particularly when patients did not receive clear or ongoing communication from their healthcare providers.

One participant highlighted that not understanding the importance of medication may cause nonadherence:

> If they didn’t realize that it’s the medication and what it’s doing, then they might think it was something else that’s keeping their diabetes under control [they may stop their meds] - ZDC8

Conversely, HCPs can educate patients on the importance of their medication to improve adherence.

> The education piece, making sure that when the doctor prescribes the medicine, that the patient understands what this medicine is going to do, how it is going to be helpful for them, and what will happen if you don’t take the medicine. So that you can be educated, be aware of it and know what to look for. Then you can make the connection and go, “I don’t want that to happen. Let me make sure I take my medicine”. -NonZDC5

Similarly, education can ensure that patients are taking medications appropriately. One participant described their appointment where they were prescribed a GLP-1 and said:

> [The doctor] sends a nurse in and shows me exactly how to use [the injector], exactly how to prepare it, how to store it, and how to administer it to myself. I had never used anything like that in my life and was only vaguely familiar, and she came in and actually administered a dose, helped me administer a dose myself -ZDC3

Additionally, participants highlighted that experiences of side effects could affect adherence. In some cases, participants who experienced side effects found that discussing their concerns with their HCPs was helpful and their HCPs were able to change their medication to a better alternative.

> I used to take [a medicine]. I absolutely despised it. It has terrible side effects, and it made me not want to take it.…. Made me constantly sick to my stomach. Who wants to do that? If you have medication that truly does not make you feel good or has side effects, then yeah, I can totally see why someone would not want to do that. -ZDC6

> I had bad side effects [with one drug] so I’d go back to the doctor, and I would tell her what was going on and how I was feeling. She’s like, “Okay, you cannot sustain this. You’re feeling too bad. Yes, you’re losing weight. Yes, your numbers look better, but this is not sustainable for you”. She took me off [the drug], put me on [another medication] - NonZDC1

As shown in the prior sections, participants experienced several system-level barriers to medication adherence including high costs and pharmacy stockouts. While participants sometimes were able to find ways to mitigate these barriers, they could not entirely alleviate them alone. Participants found that HCPs could be helpful in these cases. For instance, when high drug costs were brought to the attention of HCPs, they were able to respond by switching drugs. One participant explained that:

> My insurance paid for one particular prescription for two years, and then all of a sudden, they decided they weren't going to pay for it anymore. Where I wasn't paying anything at all for it, it went from a 0 copay up to a $450 copay. That's when I contacted my doctors and told them what happened, and this is where the switching of the medication started until we found one that didn't have that big of a charge. – ZDC8

In addition to changing medications, HCPs helped participants by offering samples and guiding them to manufacturer websites that offer discount codes.

> The other kind, the one you take once a week, they are very expensive. I think the doctor will give you a sample to start, and they might give you a coupon for a low-cost copay maybe for six months or a year. - ZDC11

> Right now—I'm in a bind right now as we speak, trying to find mine. The Synjardy website is down that was giving me discounts, so I'm stuck—and now they want $304 dollars for a one-month supply. I've been working with my doctor trying to get in touch with them in some way -NonZDC10

Another system-level barrier involved concerns with accessing medications during the refill process. For instance, as discussed, some HCPs did not always call in refills in a timely fashion. Some participants highlighted that their HCP provider had systems in place to mitigate this concern to assist with refills or delays.

> The people at the clinic I use has a portal that you can go online and ask for refills. They also have over the phone, you can either leave a message or you can leave a voicemail and they'll return it. They make it super easy. – ZDC6

> I'm talking to two different pharmacies now that I'm trying to get [my meds] from. They couldn't get [the medicine]. I asked if [my doctor] could switch me onto something else, and she did. - NonZDC1

Several participants highlighted that while HCPs could be helpful, there is a potential financial barrier to seeking support, separate from the cost of the medication itself.

> In some cases, it's—again, costs money. Because for me to get in touch with my doctor and actually talk to him, well, there's a $70 charge - NonZDC10

Theme 4: Members' Perceptions of Pharmaceutical Companies Were Coupled with Concerns About Medication Costs

Participants' perceptions of pharmaceutical companies were closely tied to concerns about the high cost of medications. While many recognized the clinical benefits of newer therapies—such as GLP-1 receptor agonists, SGLT-2 inhibitors, and DPP-4 inhibitors, they expressed frustration over their affordability. Several participants felt that pricing disparities between brand-name and generic drugs were driven more by profit motives than clinical necessity. These concerns translated into skepticism toward pharmaceutical companies, particularly regarding the fairness and transparency of drug pricing.

> It is just a brand name versus generic. Typically, it's just a name. It's just the way you dress it up. You dress it up and give it a fancy name, and then therefore, people think it's going to work absolutely wonderful, and people are willing to pay whatever. When you give it to them in a generic version, it's going to do the exact same thing. -ZDC8

Many participants believed that the high costs of drugs were entirely due to the pharmaceutical companies wanting to make money

> I think the pharmaceutical companies are greedy. They're going to take advantage of us cause the more monies they can make. - NonZDC3

> Well, I don't—you see, hear, and read about that all the time, about the big pharmaceuticals, and they're just—they're going to charge this and make their money and this, that and the other. I think some of them are just going to do it, because of the demand of this—the price and demand thing. Supply and demand. - NonZDC6

> Well, I think it's political. I think it's all politics. I think it's Big Pharma. - ZDC9

Discussion

This study explored perceived facilitators and barriers to medication adherence among individuals with diabetes enrolled in a health plan with and without a zero-dollar copay (ZDC) program. Qualitative analysis identified a range of individual, interpersonal, and structural factors shaping adherence. Four primary barriers emerged: cost (including deductibles, copays, and lack of clarity around coverage); refill challenges (such as provider or pharmacy delays, stock-outs, and competing life demands); limited understanding of medications and side effects; and distrust of pharmaceutical companies and pricing. Facilitators of adherence included established medication routines, family or social support, and strong relationships with healthcare providers that helped address knowledge gaps and system-level barriers.

The most policy-relevant finding from this study is that the barriers and facilitators described were strikingly similar among participants with and without the ZDC benefit. This suggests that while cost-removal programs may reduce financial burden, they may have limited impact as standalone interventions. Improving medication adherence likely requires complementary efforts that address behavioral, informational, and system-level barriers, including increasing patient awareness and understanding of benefit design.

Cost emerged as an important barrier, which may reflect the high price of newer medications recommended as first-line therapies by the American Diabetes Association are typically expensive and not covered by the ZDC benefit.[19] Participants also cited challenges such as competing life priorities, difficulties accessing prescriptions, and medication side effects. Participants also described strategies that supported adherence, including establishing consistent routines and working with healthcare providers to address medication-related challenges.

Despite the ZDC program's intention to reduce financial burden, participants across both groups expressed similar experiences and perspectives regarding adherence. Participants in this study described memory aids as behavioral strategies – eg. phone reminders, taking medications at the same time each day, or linking medications to routines – being important tools in staying adherent to their diabetes medications. These findings are consistent with literature showing that routine-building and habit formation significantly improve adherence among individuals managing chronic conditions such as T2D.[20,21] Beyond individual strategies, participants emphasized the value of interpersonal support, particularly among family members who reminded them to take medication, helped with prescriptions or helped them feel motivated to take medication. Prior research similarly suggests that family support can positively influence chronic disease self-management.[22–24] This support can be especially important for participants with limited digital or health literacy and those who juggle multiple life demands.[25,26]

Importantly, behavioral interventions and interpersonal support are not isolated from systemic challenges. Participants were prescribed drugs not included in the ZDC benefit– the ZDC benefit for example does not cover first-line drugs except for metformin (see Supplemental Material 1 for a list of ZDC medications). As such, ZDC and non-ZDC participants cited high copays and deductibles as barriers to adherence among either themselves, acquaintances, or hypothetical people discussed in the interviews, at times needing to skip or delay doses due to high costs. Other studies highlight similar findings and find that high costs lead to delays in filling medications. For example, one study found that up to 20% of older adults skipped, delayed, or did not take medications as prescribed due to cost.[27,28] Other systematic barriers, including pharmacy stock-outs, add additional frustrations even when patients have clear routines and are adherent. These findings highlight how behavioral adherence strategies may be difficult to sustain when reliable medication access is disrupted.

Similarly, while some participants developed adherence strategies independently, others credited their healthcare providers for helping them overcome barriers to adherence. Current literature supports these findings and found that medication adherence may be higher among patients who trust their physicians enough to openly discuss cost concerns and having trust in physicians improves self-efficacy and medication adherence in patients with chronic conditions.[29,30] Prior interventions have shown that even brief, structured conversations during clinical visits can improve adherence by identifying patient barriers and tailoring reminders or behavioral prompts accordingly.[31]

We found that some participants had strong opinions on pharmaceutical companies. Participants expressed frustration with rising medication prices, perceived profit motives, and a lack of transparency in the drug supply chain. In an era of growing mistrust in the healthcare system and declining adherence to medical guidance, these findings highlight the potential importance of strategies that strengthen trust in healthcare providers.[32]

Policy and Implementation Recommendations

Participants' experiences suggest that while behavioral and interpersonal supports can help, these work best when complemented by systemic solutions such as affordable medication access and clear communication from health plans and providers. For example, several participants described challenges related to high out-of-pocket costs, coverage for specific medications, and delays in obtaining refills. Based on these experiences, health plans may wish to consider strategies such as streamlining formulary exceptions or improving refill processes to reduce barriers. While issues such as supply chain redundancy were not directly raised by participants, the challenges described with medication availability and pharmacy stock-outs highlight the value of system-level efforts to ensure consistent access. Coordinated implementation of these steps may help shift the burden of adherence from individuals to the broader health system.

This study found that participants with and without the ZDC benefit reported broadly similar barriers to medication adherence. Several factors may explain this pattern. First, participants did not consistently demonstrate clear awareness of which medications were covered under the ZDC program, suggesting that reduced copays may not translate into perceived affordability if benefit design is not well understood. Second, many of the barriers described extended beyond cost, including delays in refills, pharmacy stock-outs, competing life demands, and concerns about side effects. Third, participants frequently referenced broader aspects of insurance design, such as deductibles and medications not included in the ZDC benefit, which may limit the perceived impact of copay elimination. Together, these findings suggest that financial assistance programs may be insufficient on their own to address the full range of barriers influencing medication adherence.

In this context, while behavioral and interpersonal support can be powerful, they function best in combination with systemic solutions such as affordable medication, clear instructions, and trustworthy relationships with the healthcare system.[33] Health plans, providers, and manufacturers may consider taking a system-level approach that addresses not only cost, but communication, trust, and consistency in medication access. Similarly, patients might benefit if providers had the tools and time to engage patients in conversations about medication effectiveness and side effects, affordability, and other potential barriers.[34] However, research suggests that current workflows make this depth of dialogue difficult.[35] Additionally, to continue combating systemic issues, programs such as the $0 copay program might benefit by considering other barriers and facilitators to medication adherence other than cost.

Our study also highlights low-cost interventions that can support adherence such as encouraging patients to link medications to daily routines. Simple tools like blister packs or pill organizers may further enhance adherence by reducing complexity and reinforcing routine.[36] Health plans may play a role in scaling these strategies by integrating behavioral nudges, providing adherence tools via patient portals, and deploying care managers to reinforce these techniques during touchpoints.[37] Moreover, these findings reinforce the need for coordinated efforts to address social determinants of health. Several participants described transportation issues, or competing life priorities that made medication management difficult. Addressing these barriers may require partnerships between stakeholders to identify and assist members at risk of nonadherence.[38]

For example, health plans might want to consider designing formularies based on clinical guidelines by covering newer first-line therapies where evidence supports their use, or by offering streamlined exceptions processes that reduce the burden on both patients and providers.[39] Pharmacies and benefit managers could consider strategies to improve consistent medication availability by monitoring stock levels, building redundancy into supply chains, and proactively notifying patients of delays or substitutions.[40] Providers, in turn, might benefit from embedded clinical tools to support conversations about cost, side effects, and barriers during routine visits.[41] Time-limited interventions, such as pre-visit questionnaires or team-based care models, can help surface these issues even in time-constrained settings.[42] Finally, health plans and manufacturers can distribute simple adherence supports such as blister packs or refill synchronization programs through mail delivery or care managers to reinforce routines at home.[43] Coordinated implementation of these steps may help shift adherence from an individual burden to a shared system responsibility.

Strengths and Limitations

This study has several strengths including its stakeholder-informed approach to interview guide development, ensuring relevance to clinical, payer, and patient perspectives. Additionally, the use of inductive and deductive coding by multiple researchers enhances the rigor of the analysis. However, the study also has limitations. The small sample size, regional focus, and T2DM specific questions limit the generalizability. Further, because questions presented to patients during the interview were based on a hypothetic person rather than the patient themselves, the perspectives provided by patients may not reflect their actual experiences. Also, most of the participants were women in urban areas, which may not reflect all perspectives of people living with T2DM in Louisiana. Regardless, this study offers an in-depth look into the lived experiences of health plan members navigating adherence challenges. Importantly, it provides actionable strategies that may inform payer policies, provider practices, and system-level changes. Additionally, as we used a vignette approach with fictional scenarios and the experiences of others such as family and friends impacted participant responses, we cannot draw definitive conclusions about the ZDC program itself without considering other areas that impact adherence. Additionally, there may have been unmeasured differences in underlying socioeconomic or employer related factors that were not directly measured between ZDC and non-ZDC that affected their experiences independently of the copay benefit design. Lastly, we do not know if patients were adherent to their medications and future work should assess these barriers quantitatively with adherence data.

Conclusion

Participants with and without the ZDC benefit described broadly similar barriers to medication adherence. These findings suggest that adherence among people living with T2DM is shaped by multiple factors beyond cost, including behavioral, interpersonal, and system-level influences. Participants also expressed concerns about medication pricing and pharmaceutical companies, highlighting the role of trust in shaping adherence. Together, these findings suggest that financial assistance alone may be insufficient to address adherence challenges and that benefit design changes may need to be paired with behavioral and system-level supports to meaningfully improve adherence. This study adds to the literature by demonstrating that, in a real-world setting, the removal of medication copays through a ZDC program did not substantially differentiate the barriers experienced by health plan members with T2D. These findings inform future policy by highlighting the need for multifaceted interventions that extend beyond financial incentives.

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Disclosure

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